

# 16p11.2 GENETIC FOUNDATION



Bringing Hope for the 16p11.2 Community



*Dr. Faranak Herrera -  
Founder of 16p11.2  
Genetic Foundation*

## MEET THE FOUNDER

When Dr. Herrera received her son's 16p11.2 diagnosis at just three years old, she quickly discovered what so many families face: there were no established medical treatments, no clear guidance, and very few resources for parents searching for answers. Instead of accepting that gap, she chose to change it.

Driven by her love for her son and her commitment to the wider community, she founded the 16p11.2 Genetic Foundation to push for research, raise awareness, and build the support network she wished had existed when their journey began. Today, her leadership continues to fuel a movement focused on understanding, advocacy, proper care, and hope for every family affected by 16p11.2 differences.

Read more about her 16p11.2 journey at:  
[https://www.simonssearchlight.org/  
Leading the Way: An Interview with Franki Herrera](https://www.simonssearchlight.org/Leading-the-Way-An-Interview-with-Franki-Herrera)

## DECEMBER: A MONTH OF INCLUSION, ACCESSIBILITY, AND DISABILITY AWARENESS

Throughout the month of December, we recognize and celebrate the rights of persons with disabilities, while continuing to reflect on the goals of inclusion and accessibility. For our 16p11.2 community, this month carries deep meaning.

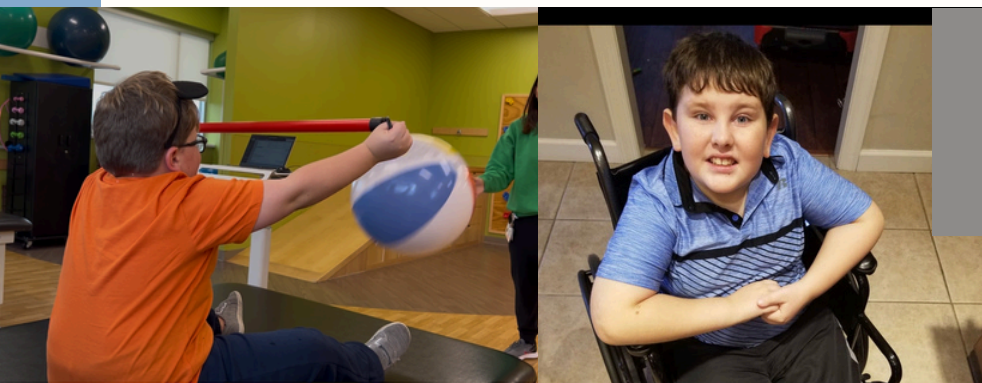
Disabilities are not defined by limitations; they are shaped by the supports, opportunities, and understanding that surround each individual. Many in our community navigate challenges related to communication, learning, motor development, medical issues, autism features, and more. Yet alongside these challenges, we see incredible resilience, creativity, joy, and strength every single day. This month reminds us why our collective voice matters.

It reminds us why we push for:

- Increased research, so families can finally get answers and effective interventions.
- Recognition, including better diagnostic pathways and the medical acknowledgment our community deserves.
- Access to therapies, supports, and services, so individuals with 16p11.2 differences can reach their fullest potential.
- Understanding, so the world sees the whole person, not just the challenges.
- Inclusion, because every individual deserves to participate, belong, and thrive.

We also honor the caregivers, parents, families, therapists, educators, and advocates who work tirelessly behind the scenes. We recognize the efforts of organizations like Simons Foundation as well as dedicated scientists and physicians who are curious. Your dedication helps open doors that were once closed and creates a future where those with 16p11.2 deletion or duplication are supported, empowered, and seen.

The month is not only about awareness, it is about action, compassion, and community. It is about building a world where disabilities do not define someone's opportunities. Where differences are understood, supported, and valued. Where no one feels alone on their 16p11.2 journey. Together, we are changing the narrative. Together, we are building a stronger, more inclusive future. This December reminds us to honor every individual who makes our 16p11.2 community so extraordinary.



*"We do it for our children."  
-16p11.2 Genetic  
Foundation*

## CHARITY MONTH SPOTLIGHT: FIGHTING FOR AN ICD CODE FOR 16P11.2

December is Charity Month. We're rallying around one powerful, long-overdue goal: securing an official ICD code for 16p11.2 Deletion and Duplication. For families, this isn't just a technical milestone—it's a turning point that can finally open the door to medical recognition, insurance coverage, and the services our loved ones urgently need. It will allow medical organizations to assess this genetic burden and scientists to identify individuals affected.

Right now, those with 16p11.2 are forced into vague or inaccurate diagnostic categories, making it harder to access therapies, justify insurance claims, or receive consistent medical support. An ICD code changes that. It provides legitimacy, visibility, and a concrete path for treatment coverage.

### WHY IT MATTERS:

- Insurance barriers make essential therapies harder to access
- Medical systems don't track 16p11.2, slowing research
- Patients are overlooked without a recognized diagnostic code
- Families bear the financial burden for medically necessary care

### HOW YOU CAN HELP:

Help us secure an official ICD code for 16p11.2—unlocking insurance coverage, medical recognition, and better care for our community.

Your gift funds:

- Advocacy and medical coding applications
- Research partnerships
- Scientific documentation
- Policy support and expert consultation



**Fighting for an ICD Code for 16p11.2**  
Fighting for an ICD Code for 16p11.2 will be rallying around one powerful, long-overdue goal: securing an official ICD code for 16p11.2 Deletion and Duplication. For families, this isn't just a technical milestone—it's a...



<https://www.zeffy.com/en-US/donation-form/donate-for-16p112-proximal-deletion-to-have-its-own-icd-code>

# **RESOURCES**

## **MEDICAL DEVICES**

### **• United States:**

- Alaska: Alaska Mental Health Trust Authority  
[https://alaskamentalhealthtrust.org/alaska-mental-health-trust\\_authority/grants/mini-grants/developmental-disabilities/](https://alaskamentalhealthtrust.org/alaska-mental-health-trust_authority/grants/mini-grants/developmental-disabilities/)
  
- California: Wheels to Walk  
<https://wheeltowalk.com/>
  
- California (Coachella Valley): Variety the Children's Charity of the Desert  
<https://varietyofthedesert.org/>
  
- Colorado: Friends of Man  
<https://friendsofman.org/colorado-assistance/>
  
- Colorado: Sister-Bear Foundation (Adults Only)  
<https://www.sister-bear.com/assistance-program>
  
- DC: Variety the Children's Charity of DC  
<https://varietydc.org/grants/>
  
- Florida: Variety the Children's Charity of Florida  
<https://varietyflorida.org/>
  
- Georgia: Variety the Children's Charity of Georgia  
<https://www.varietyofgeorgia.org/#/>
  
- Idaho: Wheels to Walk  
<https://wheeltowalk.com/>
  
- Iowa: Variety the Children's Charity of Iowa (Transportation and Medical Bills)  
<https://www.varietyiowa.com/grants-programs/grant-program/>
  
- Illinois: Variety the Children's Charity of Illinois  
<https://varietyofillinois.org/how-we-help/>
  
- Kansas: Sister-Bear Foundation (Adults Only)  
<https://www.sister-bear.com/assistance-program>

## **RESOURCES PAGE 2**

- Michigan (Detroit): Variety the Children's Charity of Detroit - All Needs  
<http://variety-detroit.com/>
  
- Missouri (Kansas City Area) Variety the Children's Charity of Kansas City - Helps with Development and Physical Delays  
<https://varietykc.org/get-help/>
  
- Missouri (St. Louis): Variety the Children's Charity of St. Louis - Medical Equipment and Therapy  
<https://varietystl.org/impact/>
  
- New Hampshire: Harry Gregg Foundation  
<https://harrygreggfoundation.org/grantinfo/>
  
- New Mexico, Sister-Bear Foundation (Adults Only)  
<https://www.sister-bear.com/assistance-program>
  
- New York: Drake Foundation  
<https://www.dakefoundation.org/grants/>
  
- Oklahoma: Sister-Bear Foundation (Adults Only)  
<https://www.sister-bear.com/assistance-program>
  
- Oregon: Wheels to Walk  
<https://wheeltowalk.com/>
  
- Pennsylvania (Pittsburgh): Variety My Voice  
<https://www.varietypittsburgh.org/my-voice/eligibility/>
  
- Texas: Sister-Bear Foundation (Adults Only).  
<https://www.sister-bear.com/assistance-program>
  
- Washington: Wheels to Walk  
<https://wheeltowalk.com/>
  
- Wisconsin: Variety the Children's Charity of Wisconsin  
<https://www.varietywi.org/get-help/freedom-grant-application/>

## **RESOURCES PAGE 3**

- **Canada:**

- Alberta: Variety the Children's Charity of Alberta  
<https://varietyalberta.ca/go-baby-go/>

- British Columbia: Variety the Children's Charity of British Columbia  
<https://www.variety.bc.ca/support/#child-grants>

- Manitoba: Variety the Children's Charity of Manitoba  
<https://varietymanitoba.com/programs/special-needs-program/apply/>

### **TRANSPORTATION**

- Southern California: Variety the Children's Charity of Southern California  
<https://varietysoocal.org/how-we-help/grants/>

### **HELP WITH MEDICAL BILLS**

- **United States and Canada:** Oracle Health Foundation  
<https://www.oraclehealthfoundation.org/pediatric-grants/>

- British Columbia, Canada: Variety the Children's Charity of British Columbia  
<https://www.variety.bc.ca/support/#child-grants>

- New York, USA (Buffalo & Western New York): Variety the Children's Charity of Buffalo  
<https://varietybuffalo.org/grants-programs/grant-programs/>

### **OTHER RECOURSES**

- Ontario, Canada: Variety the Children's Charity of Ontario  
<https://varietyontario.ca/programs-locations/>

- Nevada, USA: Variety the Children's of Southern Nevada  
<https://varietyasn.org/community-programs>

- New York, New Jersey, and Connecticut, USA: Variety the Children's of New York  
<https://varietyny.org>

- Pennsylvania (The Delaware Valley), USA: Variety the Children's of Philadelphia  
<https://varietyphila.org>

- Tennessee, USA: Variety the Children's of Eastern Tennessee  
<https://www.varietytn.org/community-grants>